COMMONWEALTH OF KENTUCKY
CABINET FOR HEALTH AND FAMILY SERVICES
DEPARTMENT FOR MEDICAID SERVICES

IN RE: CHILDREN'S HEALTH TECHNICAL ADVISORY COMMITTEE

November 13, 2019
2:00 P.M.
Cabinet for Health & Family Services
Café Conference Room
275 East Main Street
Frankfort, Kentucky 40601

APPEARANCES

Lisa Powell
CHAIR

Mahak Kalra
Donna Grigsby
Pat Glass
Cherie Dimar
TAC MEMBERS PRESENT

Judy Theriot
Sharley Hughes
MEDICAID SERVICES

CAPITAL CITY COURT REPORTING
TERRI H. PELOSI, COURT REPORTER
900 CHESTNUT DRIVE
FRANKFORT, KENTUCKY 40601
(502) 223-1118

APPEARANCES
(Continued)

LeAnn Magre
WELLCARE

Cathy Stephens
Felicia Wheeler
HUMANA-CARESOURCE

Mendy Pridemore
AETNA BETTER HEALTH

Rae Bennett
ANTHEM

Jessica Beal
Cheri Schanie
Courtney Henchon
PASSPORT

Jerry Caudill
AVESIS

Tal Curry
OFFICE OF AUTISM

Alicia Whatley
Maanasa Manchikanh
KENTUCKY YOUTH ADVOCATES

AGENDA

1. Welcome and Introductions

2. Establish Quorum

3. Approval of September Minutes

4. NEW BUSINESS
   * Autism Spectrum Disorder - Dr. Greg Barnes
   * Topics for 2020 meetings
     January - vaping, e-cigarettes
   * Updates from the MAC - Mahak Kalra
   * Roundtable Updates/concerns from each member/ professional organization

5. OLD BUSINESS:
   * DMS on Kentucky Integrated Health Insurance Premium Payment Program (KI-HIPP)
   * Psychopharmacological prescribing for KY children
   * School-based services and Free-Care Rule

6. MCO Updates/Questions or Data Request Reporting

7. General governance issues

8. Other Business

9. Action Items

10. Adjourn

MS. KALRA: We are waiting for Dr. Barnes to arrive, but I know we don't have a quorum based off of the number of folks that we have in the room, but we can definitely introduce ourselves and talk about the other topics before we move forward.

(INTRODUCTIONS)

MS. KALRA: Now that we've introduced ourselves, we don't have a quorum, so, we will move on from the establishing quorum and approval of minutes.

New Business, we will wait until our speaker, Dr. Barnes, gets here so he can continue the conversation that we've had last quarter about autism and seeing what we can do as a TAC to recommend any recommendations that might be helpful.

And, then, the other thing that we wanted to talk about was topics for 2020. We were thinking about January talking about vaping and E-cigarettes, but to follow up on the next bullet point which is talking about updates on the MAC, I was at the last MAC meeting and we talked a lot about the U.S. Census and how this upcoming year is when we do the census again and children are often undercounted when it comes to the census, and it just

reminded me how important our TAC could be and valuable in helping that and spread that message.

So, if it's okay with the members that are here, thinking about maybe making January our discussion on census. That way we could come up with strategies or recommendations, given that the census will happen in April, so, just getting us ready to go for that and at least talking amongst our different provider groups and perspectives.

And, so, if that is something that TAC members they feel appropriate, I think we should move forward with that. I don't know if anybody has any concerns or other suggestions or thoughts.

DR. GRIGSBY: I think that's a good idea. I think that certainly it was felt to have a big impact that a lot of children were undercounted at the last census and that affects funding and all kinds of important things.

MS. GLASS: Has anybody heard any idea if they're going to somehow coordinate with the school systems for the census?

MS. KALRA: I'm not sure but that could be a potential recommendation.

MS. GLASS: At least you'd get an accurate children count at least for part of it anyway.

MS. KALRA: I know this year is supposed to be electronic, I believe, but I'm not sure of other steps or avenues but that just stood out to me at the MAC how we as a Children's Health TAC, that's our primary audience, so, if we could do something, we certainly will.

(Dr. Barnes enters)

Here is our speaker. So, if everyone is okay with that. Hello, Dr. Barnes. If you could have a seat right here. We are just getting started. We just went ahead and moved on to some other business.

So, if that makes sense with everybody, I can try to find a couple of speakers. I know one actually spoke at the MAC meeting that I could reach out to and I've got her card and I know that in the office, we are working diligently on efforts that we could do as a state and, then, also as local communities can do.

So, if that's something that everyone feels comfortable and confident with, I will make a motion to move forward with that. I see

shaking heads. So, that's a yes?

DR. GRIGSBY: Yes.

MS. GLASS: Yes.

MS. KALRA: Okay. Sounds good. So, I will make that a priority for next meeting.

That also touches base on the MAC update. That was one big presentation that was happening there. Other than that, I don't recall any other point that was valuable to share to this group. Does anyone from DMS recall anything else that might be relevant for this group?

MS. HUGHES: No, I don't. My mind is drawing a complete blank right this very moment.

DR. THERIOT: All I can remember is urine drug screenings.

MS. HUGHES: They did ask about our new urine drug screening, so, she talked about it a little bit.

DR. THERIOT: The census lady was really good.

MS. KALRA: Yes. She stuck out to me. That was the high level part of the MAC meeting that I remember that I was going to take back and talk about. All right. Well, that rounds out

those two things.

Dr. Barnes, are you ready or do you want me to give you a couple of minutes?

DR. BARNES: Give me a couple of more minutes here.

MS. KALRA: Okay. Sounds good.

MS. HUGHES: Before you move on because I don't see that you have the meetings on there, but I've sent everybody the meeting dates for next year. So, if you wanted to just go ahead and talk about that.

MS. KALRA: I think we approved them last time. It might be good if we send out the dates again so that way everyone has them on their calendar. So, if you want me to do that, I'm happy to do that.

MS. HUGHES: That's fine. I can give them out here, too.

MS. KALRA: That's perfect.

MS. HUGHES: January 8th, March 11th, May 13th, July 8th, September 9th and November 11th and those have all been reserved for this conference room, so, it will be easier for everybody to get to and easier to find and I have it from 2:00 to 4:00.

MS. KALRA: Okay. Great. And, then, also, this is the same structure as we had before. So, Wednesdays, 2:00 to 4:00. Nothing has changed in that regard, so, just the same process as always. They're all Wednesdays from 2:00 to 4:00. Thank you, Sharley.

Whenever you're ready, Dr. Barnes.

DR. BARNES: First off, let me just introduce myself and tell you a little bit about myself.

COURT REPORTER: I'm going to ask you to keep your voice up.

DR. BARNES: Sure. My name is Dr. Gregory Barnes. I'm the Director of the University of Louisville's Autism Center and I'm also the Co-Director of the Pediatric Epilepsy Program at Norton Children's Hospital.

By those titles, you can tell that I'm both a pediatric neurologist interested in neurobiology disease and I'm also a trained epilepsy doctor, an epileptologist.

I'm also the father of a twenty-six-year-old who has autism. His name is Joshua. Joshua is moderately affected. He does walk

and talk. He doesn't live independently but he lives with us and he does have a job and, like many young adults with autism, is very delightful.

So, I've had a journey in autism that is both professional as well as personal. I have basically lived it 24/7 365 for the last twenty-six years.

So, before I go ahead and start talking, I just want to have a little bit of an idea of my audience because I didn't get really a sense of that. So, how many medical professionals do we have here? We've got four medical professionals. And who are our other types of folks around?

MS. KALRA: So, there's different advocacy groups. So, we have the PTA. We have myself with Kentucky Youth Advocates, the Nurses Association, so, a variety of provider groups.

MS. HUGHES: Folks around the room are managed care organizations.

DR. BARNES: Of course, that's my son calling because it's 2:00 and he always calls his dad right after 2:00 because he gets off work at 2:00. I apologize for that. Now it's my wife. She forgot.

MS. KALRA: Are you sure you

don't want to take that?

DR. BARNES: I'm sure. If it's an emergency, she will call back. She may have remembered when she hung up then.

So, as you guys well know, autism is really defined by the impairments in communication, social skills, sensory interest and they have this very, very sort of specific type of disability in which they do repetitive behaviors and they have this so-called circumscribed-specific interest or restricted interest.

That's the one thing that I think before I really got interested in autism that I really didn't quite understand. Well, I can tell you that I now understand it very well. My son loves Marvel movies and he will call and talk about Marvel movies. That's what he would talk about on the phone. So, they become very, very focused on very specific things and they really think about it over and over again.

The thing that most people don't really understand about autism, even though it's primarily a disorder of the brain, is that it's really a multi-system disease and there are a variety of individuals that really help us take care of these

patients.

You all heard a little bit about last time - and thank you for having Tal, by the way - you heard a little bit about our multidisciplinary medical autism and diagnostic clinics in which we have developmental pediatricians, psychologists, pediatric neurologists, child psychiatrists, etcetera.

But what you may not know is that you also need a sleep doctor because they have sleep disorders. You need a GI doctor because they have GI problems. You need your geneticist because oftentimes these individuals, it's mostly a genetic disease and they're actually born with these so-called spontaneous mutations. Those are so called de-novo mutations, and those may involve areas of our DNA that involve other organs.

For instance, one of the things that I look more and more for because I've seen it more are heart arrhythmias. I don't know if anybody in the room has actually heard of autism patients having heart arrhythmias but, in fact, they do. They have Wolff-Parkinson-White, they have prolonged QT interval, they have a variety of things. So, we need our pediatric cardiologists as well.

Many of these individuals are also - how should I put this politically correct. They appear larger than the normal folks for their same height. They all report themselves as, and, in fact, the young adults all report themselves as being overweight.

So, the problems that go with being overweight, diabetes. I was just seeing a kid today who is about my height and 343 pounds. He was something. He was something else.

So, it's very important for us to actually have the endocrine doctors that are on board as well, and that's in addition to all of our different specialists in behavioral mental health, and I think Tal talked about that last time in detail.

One of the things that you may not - Tal, did you go over some of the economics in autism or not?

So, whenever I talk about autism, I want people to get a good sense of how much does it cost. Well, over an individual lifetime, the excess cost is between $3.5 to $5 million over a lifetime.

To give you context about that,

this year, Alzheimer's disease and autism will cost the same for the U.S., about $266 billion. In 2050 when we're supposed to have this huge amount of patients with Alzheimer's disease, you know, they've talked about the graying of the population, Alzheimer's disease will approximate $300 billion. Autism is going to approximate about half a trillion dollars a year to the U.S. in terms of excess costs.

And you talk about the financial burden to the families. When I had my child going through ABA and all types of behavioral therapies, in all due difference to all the managed care organizations, fifteen years ago, it wasn't as well covered. So, I was paying about $50,000 a year roughly just to get his behavioral therapy.

And the other thing that you all may not be familiar with is because of the impacts of autism, the average autism family for a given level of training and the same job earns about 30% less due to a variety of factors, including time out of school, time out of work because you have to pick your child up because of behavioral issues and all sorts of other things like that. So, those are huge, huge challenges.

I think Tal talked a little bit

about the fact that we have no centralized data mechanisms for the state and that certainly is one of our goals of the ASD Council.

I will just give an example from the education here on the slides. In 2007, according to the census, there's about 7,000 students under the age of eighteen who should have had autism in the school systems. The actual documented number was 2,367 according to the Kentucky Department of Education statistics.

So, this is a huge challenge in terms of documenting both in the educational realm and other types of realms that you actually have a person with an autism diagnosis. So, that's a huge, huge challenge.

And that's part of the response and the reason why the Council came to be. And I'm not going to go over the Council other than just to say that we were formed by the bill that was signed by the Governor in April of 2016.

If we projected a map of where autism patients are, we don't exactly know. However, based upon our census data, the University of Louisville and others have generated maps showing where we think they are which is in the major

population centers and obviously most concentrated in Louisville and Lexington and other places, too, Warren County and Daviess County and some of the other counties where we have our towns that have significant populations.

And that strategically is actually where we placed a lot of our medical consultation centers and our diagnostic centers to try to move care to a more central location for them, and it's difficult for the parents to get there.

One of the things that is a great challenge in autism and I refer to it as identification is that because we don't have real good instruments to really be able to measure the types of symptoms that we have in autism.

We have some scales to measure some of the medical complications and those are fairly easy to get a handle on, but what is harder to get a handle on is behaviors. Unless you actually have a videotape that will actually kind of show you exactly what the patient is doing, it's hard to describe that in a parent-report instrument itself.

And as I note here on the slide, it's really hard to be able to measure that as a specific output and from a specific brain region.

And that's actually very, very important. Right now we have broad instruments that are in play for treatment and those instruments which are mainly behavioral therapies work on multiple different areas of the brain. And if you indirectly measure those outputs of those areas, then, things like OT and speech, they will impact multiple symptoms for multiple brain regions.

But in the future, there is going to be much, much more in the way of specific medications that are going to try to address specific symptoms that come with specific brain regions. So, we really need to have some real good instruments that are able to do that and those instruments really don't exist right now.

A good example of our problems with those instruments are the M-CHAT. Tal, did you talk about the recent M-CHAT data or not?

MR. CURRY: No.

DR. BARNES: So, as everybody knows, you may have heard of this test. It's called the M-CHAT that's administered to toddlers. It's mainly administered by our general pediatricians who are seeing patients as a primary care doctor, and it's one of our main screens for autism. The STAT is

another one.

But there was a recent study that showed that the M-CHAT actually misses 70% of patients who prospectively end up getting diagnosed with autism. So, our screening tests are also not very good.

COURT REPORTER: Keep your voice up.

(Dr. Powell comes in)

DR. BARNES: Sorry about that. There are a lot of different types of therapies and I won't go over those, but just to summarize for the evidence-based practices that we have, so, we have very good evidence for a wide variety of behavioral approaches that positively impact cognitive skills, social and communication skills and adaptive skills.

We've got just a little bit of treatment now for different pharmacological symptoms, i.e. the types of medications that I would normally use. And I always like to tell autism parents I'm about 20% of the solution simply because what I mostly recommend are other interventions other than medications.

Unfortunately, we do not have a lot of good evidence for best practices to treat

comorbidities. What's best practice to treat neurological disease? What's best practice to treat sleep? What's best practice to treat GI symptoms?

We're working on those in various and sundry research networks but the bottom line is that we don't have good evidence from randomized controlled trials.

So, our future, of course, is this multidisciplinary approach that Tal was kind enough to describe to you guys that involves not only the medical professionals as a team but also includes your therapists, includes your school's input, etcetera. And this is actually what we try to do in our medical consultation clinic is that we try to bring all of those together.

The problem with those, of course, is cost. How do you cover all of those costs? One of the things that Tal probably didn't talk about is the multidisciplinary clinics. Roughly, the income that we generate from our MCO friends covers about a third of the cost and the rest of it has to be covered with Title X dollars.

So, it's very difficult to cover just for reimbursement alone a multidisciplinary approach which is really the best

type of approach to have with patients.

I'll point out that the multidisciplinary approach can lead to incredible cost savings. I'll just point out one particular therapy that we are trying to as an autism community to try to train more providers and get that therapy out there, i.e., early intensive behavioral intervention and ABA.

So, if you do EIBI for two years, from ages three to five, the cost I enumerated to you, it's roughly about $100,000. Anybody got an idea of how much money you save over a lifetime when your IQ goes up twenty points from that intervention? Anybody?

So, the rough savings is about $1 million over a lifetime. So, that can cut your costs from three to four million down to two million and that's just one intervention.

There are a number of different economic studies to show that as you implement evidence-based practices in autism, for every buck you put into that, you save about $10 to $15, and it varies from country to country, etcetera, but it really is something that is quite cost effective.

And it's even effective in the

short-run. If you look at some of the studies from the EIBI and the cost of it, it's initially $300 more expensive than standard therapy, but by two years out, the cost (inaudible) are actually reversed. The standard therapy is $300 more and the traditional therapy that's follow-up to EIBI is much less.

So, you're actually generating even short-term savings for the amounts of your standard therapy that you're getting after evidence-based practice. So, it can lead to cost savings even in the more short term.

Tal went over a lot of the things that are challenges for services in the state, very few in the way of pediatric providers, both on the medical side, but also a therapist or a psychologist or BCBA's.

Tal, did you talk about the ABA's and where they're located just to give them kind of a sense?

MR. CURRY: No.

DR. BARNES: Okay. So, if you look at all of the BCBA's in the state, half of them are located in Lousiville. So, eighty-eight of them are in Louisville. The other eighty-eight are dispersed out through the state, even though

Louisville only has a quarter of the state's population.

So, outside of Louisville and even in Lexington, there's a real dearth of trained BCBA's and they are the ones, of course, that really spearhead a lot of our very, very effective interventions.

So, these regional disparities are a real issue with us and it also extends to occupational therapy and speech therapy and other types of therapy as well, and that's just in the pediatric population.

If you look at some of our adults, our adults really have huge problems. First off, at least with Lousiville and Lexington, there are at least some specialized pockets of pediatric providers that can provide evidence-based care, but in Kentucky, we basically just have two centers, one in Louisville which is the Lee Clinic, and, then, the other one which is in Eastern Kentucky, Oakwood, that provide care to not only autism patients which is about half of who they care for but also the other half are all the others with intellectual disabilities.

And if you listen to the adults

with autism talk, there are so many different barriers that they talk about in terms of accessing health care. If they can talk, they're afraid to call on the phone because they're so anxious that they're not going to be understood. There's lots of different barriers like that. So, it's a real issue for them.

And the needs are huge. I think Tal went over a number of those in the handout that he sent. I'll just reinforce them, and they really come in really six categories. One, more highly trained and autism-knowledgeable workforce and population centers across the state serving inside and outside of the waivers.

I think Tal talked about some of the barriers to access as a result of providers wanting to be inside the waivers as opposed to outside of the waivers because reimbursement is more inside the waivers.

Another thing that we really, really need for not only our newly-diagnosed families but I would also argue for our adults, too, is really to have a mechanism for more knowledge acquisition of the sources either through paid case management or through a family navigator type model.

The Autism Council, we have latched onto that family navigator/family leadership model and we're trying that out now. I think we're still in our early stages. Would you agree, Tal?

MR. CURRY: Absolutely.

DR. BARNES: Absolutely. Especially as patients get older, to have that ability to be able to navigate the medically complex systems, especially as you're transitioning from pediatric providers to adult providers. So, whether you're talking about school or you're talking about jobs, all these sorts of things, it really could be quite helpful.

I must say that I have seen that close up myself. Joshua has the Michelle P. Waiver and he has a case manager as a result of that. And, so, we have navigated a lot of different difficulties at work because of that. He works at UPS but there's still lots of behavioral things that come up during that time. And having that case manager there has been huge for his experience, and as a result, his experience has been addressed in a realtime fashion.

Joshua's development has grown and grown and grown and grown, and that goes with the

data that's from the University of Wisconsin, the Waisman Center. They actually have done a prospective study of about 1,000 adults with autism and they followed them from their thirties all the way to their seventies. And while there's some suggestion that there is some falloff in skills, for the most part, for the most part, skills are usually maintained.

But the key to the development and maintenance of those skills from high school on up is only two factors - only two. They looked at 160 different factors, from medical factors to psychosocial factors.

Anyways, so the bottom line is that, one, having a positive person in your life to help encourage you and, two, access to services. Those are the only two things that matter to adult development in autism.

And you can think about development in autism as not ending at twenty or twenty-five. It actually continues through decades, okay, and that's important to grasp. And I'm sure that if there are other studies out there about intellectual disabilities, that you would probably find that in other intellectual disabilities as well.

So, I think that being able to navigate a system as an adult and having that sort of, what you were talking about, case management with family navigators, etcetera certainly is a critical thing for their development.

Tal talked about this last time. I'm going to address it just a little bit more. We have a lot of families that really are quite distressed. Usually these involve families with teens, early teens or maybe young adults who have more difficulties in expressing their communication and as a result they act out.

There's really not that many in terms of behavioral health providers that can really provide these intensive, in-home and community-based therapies. There's a real inability to be able to access crisis stabilization services and short-term crisis stabilization units and that's a market thing that I and Dr. Lohr and Dr. Yoder, my two child psychiatrists at the Autism Center, we get calls from Western Kentucky, Eastern Kentucky, we get calls from all over the state about families who are in these sort of troubles. And I think that is a huge issue in the autism population and that really spans both pediatrics and adults.

And, then, finally, as I talked a little bit about both for youth and adult as well as families to having these peer support services are also a tremendous challenge and something that is really quite needed.

So, that's a short little introduction.

MS. KALRA: Before we go into questions or discussions, do we want to introduce a couple of the new faces that walked in during the presentation?

(INTRODUCTIONS)

MS. KALRA: Do we have any questions for Dr. Barnes?

DR. BARNES: Tal, do you have anything you wanted to add to what I said?

MR. CURRY: No, I think you've covered it pretty well. I think just getting feedback and see what questions you all have.

MS. KALRA: Anyone have any questions to start off with? I know one question that I had was you mentioned there's no centralized data mechanism.

So, something that we often say at KYA is what gets measured gets changed. So,

thinking along that line, in a realistic estimate, what does that look like? How much would that cost and what would that bring to your organization and how would that help you?

DR. BARNES: In terms of us being able to track lots of different things, it would be incredibly useful. For instance, now we have a contract actually with the State to look at the economics of genomic testing in patients with complex neurological diseases. That's a collaboration that we have with the Cabinet and the pediatric epidemiology units/the CAHRDS unit at U of L.

And we're going to answer a very, very central question, i.e. what is the most cost-effective way to do genetic testing in a given population, and that's just a very small example of how we could look at the economics of this.

We can certainly look at the utilization of services which we really don't have a real good clue about at all. We'd love to know where the patients actually are. That would be nice, huh? And it could help us with targeting not only services but also, most importantly, for those of us who are educators, understanding how we can find, train and

encourage providers to go back to particular areas.

I don't want everybody to come to Louisville. I'd much rather providers to actually stay where they are. We have one program that I will just mention. Dr. Theriot helped me start this off and we're slowly but surely getting it off the ground with the new Office of the Children with Special Health Care Needs (OCSHCN).

It's a model that's called ECHO, and essentially what ECHO is is ECHO Autism Clinics are a forum not for patients/telehealth but it's actually a forum for providers to, one, get small lectures on given topics and autism, but, two, it's actually driven mostly by case-based learning.

We have one of our primary care physicians bring an autism case to the clinic that might have twenty or thirty or even more people on various trainings. And what you have as your panel is a panel of not only MD's but also psychologists, educational consultants or whatever else may be the issue in that case.

And the panel leads the discussion of the case, pointing out the salient points of evidence-based care for a patient, whether you're talking about what's the evidence for treating

sleep, what's the evidence for treating irritability, what is the evidence-bases practices in education.

And, so, it allows a large learning community of providers in their own offices throughout the state to be able to impart knowledge in autism.

So, that's just an example of something that would be incredibly useable to be able to impart knowledge and direct providers and population centers to help care for patients.

Now, what it would cost I have no idea. I'll leave that to people who are more knowledgeable about those things because I'm just the lowly physician. I'm not the IT guy.

MS. KALRA: With the ECHO, is it that right now the challenge is not a lot of providers know that it exists? Is it something that we could help as the TAC sharing a message with our groups?

DR. BARNES: Certainly as it gets off the ground, you will be hearing more about it. So, we're happy to share information about it, but the idea, at least in the area of autism and of mental health, is to be able to in an adult learning way through case-based to share information at

essentially just at a provider's computer at the office.

Dr. Williams--does everybody know Dr. Williams? Anyway, Dr. Gail Williams is really the senior pediatrician in autism in the state. She has been practicing for well over thirty years. I wish I could keep her another thirty years but that's probably not going to happen. So, that's the reason why we're training new ones.

Anyways, Gail did and published a study in 2012 looking at just the medical knowledge of patients with autism with particular problems. If you have a problem that comes in with sleep or a problem that comes in with GI issues or neurological problems such as seizures, how confident does a pediatrician feel in treating those disorders? And the answer to that question is 25 to 50% felt that they had some knowledge, but it was 25 or 50%.

And Judy can correct me if I'm wrong, but I'm sure that the primary care pediatricians feel the same way about many of the other behavioral health issues that come in to their offices, and 20 to 30% of their visits are now pediatric behavioral health.

MS. HUGHES: May I ask a

question as a non-TAC member and a non-Medicaid employee?

DR. BARNES: Sure.

MS. HUGHES: You mentioned in 2007 that there was an estimate of 7,000 students under eighteen should have been marked as having autism.

DR. BARNES: By the education system, yes, but there was only 2,300 that were actually identified.

MS. HUGHES: So, how does the Education Department--does that have to be reported by a parent or is it through testing that's done in the school system?

DR. BARNES: Well, do our psychologists want to explain the educational diagnosis of autism? I would defer to them. I think I understand it but I would rather let them do it.

DR. POWELL: So, it is often a challenge and I am often in school meetings where we're having that discussion. So, a child who we have already done a full evaluation on has a diagnosis of autism, but in the school system, they have different eligibility categories and, so, the child needs to meet eligibility in the education

realm that's separate from a medical diagnosis.

So, the real question that they're trying to ask is does whatever is going on with the child negatively impact their ability to receive an education? And, so, that is a different diagnosis often. So, it isn't just that. Sometimes they don't meet criteria from an education eligibility standpoint.

The other issue that we see often is that in the public school system, kids go under just developmental delay until they're nine years old, but often those children already have a diagnosis of autism but that's not reflected in the school's eligibility categories or in terms of the services that they are receiving. They're still under development delay until they're reassessed at nine and, then, maybe they go enter an autism diagnosis or category.

MS. GLASS: And all of that is under IDEA. It's all federal.

MS. HUGHES: I was just curious because that seemed like a stark difference. To me, I was thinking there was probably more than 7,000 students under eighteen that would meet that autism category.

DR. BARNES: This is something that the Kentucky Autism Training Center is continuing to address. Does everybody know what the Kentucky Autism Training Center is? Most people? Yes, no?

Well, anyway, so, Larry Taylor and his colleagues have really been trying to get into the schools and impart the knowledge that they need to make these eligibility criteria designations to understand better.

Even if a child still has a medical diagnosis of autism, how do you implement evidence-based practices to help that individual child?

And we have a lot of different mechanism both for training at a--they have a lot of different mechanisms for both training at the school at a district level to bunches of teachers and, then, we also, through our medical consultation clinics, we have sort of a more individual consultation service.

So, as we hear about students who are having some difficulties in school, we actually have different trainers - we call them school trainers - that go out and actually look at the individual parents/student's situation to see if

we can try and address that, and that includes a lot of referrals for students who are currently getting in-home schooling. We try to, if possible, try to reverse that because the child needs to be in school and be educated. There are so many different advantages of that versus in-home schooling.

DR. POWELL: Can I ask you a followup question about the BCBA issue? First, I practice in Louisville and I know how hard it is. I can't imagine what it's like in the other parts of the state trying to find providers, but can you give some more detail about those practitioners? Are they Medicaid providers or lots of them outside of, you know, or maybe they're in private insurance.

DR. BARNES: That's a good question. I don't have a real good sense of how many are inside versus outside of the waivers. Maybe our managed care folks do but I don't have a real good sense.

All I do know is that the reimbursement is higher and you tend to have a long waiting list, and people who have the Michelle P. can get services, but those that have Kentucky Medicaid and all the managed care organizations, because the reimbursement is lower, end up on waiting lists and

that's the real problem.

Patients who need the maximum time for effective intervention is in this three- to six-year age group and that's the age group in which, if you do the training/therapy, you can make a huge dent in terms of their development, change their trajectory and, as a result, have a lot of health care savings, but people spend a year, two years on those waiting lists to be able to access those services.

Let me just explain that a little further why those years of three to six. So, there are many different systems in the brain that are developing between the ages of one to six years of age and they all have a window of time that's called a critical period.

And what that is from a point of view of just everybody understanding it is that if you implement therapies during those critical periods, patients are more likely to wire their nerve cells more correctly together than they would be if they didn't have the therapy.

And that's what all our therapies do is that they actually impact, first off, the strength of how nerve cells talk together and,

two, how the wires actually connect up. And autism is really essentially a disease of mis-wiring. We call it developmental disconnection syndrome in the autism research community, but that critical period is a window of time between one to six years of age where that the impact of that therapy on getting wiring corrected is much greater versus after six years of age.

For instance, speech therapy, that's one of the areas in which if you're not speaking by six years of age, it's unlikely that speech therapy is going to be tremendously effective going forward.

Anyway, so, that's a long answer to your question. I wish I could tell you the answer to that question but the answer is really many-fold. There has to be more education, number one. There has to be more schools that are putting out BCBA's. Number two, we've got to look at the models of reimbursement and see what we can do to be able to encourage access by all patients, not just those that are lucky enough to be on waivers.

And another thing, our friends around the room told me this when I first asked about this, our BCBA's need a lot of business education.

They really do. They need to have a better understanding of how to be able to access funding mechanisms for their services. Those groups that are more successful in the state such as Bloom Therapy, they've got one office manager that that's all she does. She understand the business of accessing BCBA therapies better than most people in the state, but there are ver, very few knowledgeable people that understand that business model.

So, one of the things I charged my faculty with is that they need to educate what's in the professional organization, as well as obviously educate their students on how to do the business of BCBA's.

DR. POWELL: Just one followup question on that. Do you know if there is much being done with BCBA or ABA work with telehealth and how that might create any opportunities?

DR. BARNES: So, that's something that has been looked at in autism. There are some evidence-based practices for that, although it's slowly but surely evolving.

It is effective. Head to head against in-person/clinic versus telehealth, I don't know that we've done that randomized clinical trial

yet, but those opportunities are there.

Certainly, from a medical point of view, we've done that in spades. We have had some pilot projects that have been done by our psychologists doing things like parent training and other things like that. Parent training is a very effective model for behavioral modification.

In fact, I'll tell you a story about China. So, I've had the opportunity to actually tour autism centers in China. Yeah, they have a few therapists that are doing clinic-based training, but most of what's done in autism clinic training is parent training. They start at 8:00 a.m. and they run those families until midnight. They have lots of people they need to see, so, it's an hour at a time, but they're big believers in it.

And the other reason why they're big believers in it is because, in China, there's not that much access to funding mechanisms as there is here. So, they get a very small amount of money to cover all of their health care and medicines are very expensive. So, medicines are hardly actually done, bu what is available and free are clinic-based visits. So, they do a lot of parent training.

So, parent training is something that certainly is being looked at at least in this state.

MS. KALRA: Any other questions?

DR. BARNES: Any other questions or comments?

MS. KALRA: Do you have any questions as a pediatrician?

DR. GRIGSBY: I think the thing we struggle most with is just connecting patients with services. And certainly even in Lexington, we are challenged I think it sounds like much more than you are even in Louisville.

How do we get past those barriers for families? It's tough because it's tough to get kids in for evaluation. And, then, once you get them evaluated, it's tough to get them referred to the services they need because the providers aren't there.

What should we be doing as a state to push this agenda forward for our families?

DR. BARNES: The most effective thing that I think that the Council is addressing is really creating that community network, that network

of parents.

And that's part of the reason why the KATC has a nerve center. They have one parent trainer that tracks all of the--there are fifty different parent groups across the state and they track those groups and provide training with those groups and refer parents to those groups as well.

And if you ask me, I as a parent, how did I get my son services, it was by talking to community advocates, other parent advocates. It's this parent navigator model that is a tremendously useful thing for parents. It really is.

So, how do we as a state encourage those types of models? We're doing it some at the Council level. Judy was there at the OCSHCN when they created the Family-to-Family Program. Judy, do you want to explain what the Family-to-Family Program is?

DR. THERIOT: It's basically a parent navigator program. So, you have parents that have children that have disabilities or chronic illnesses and have most of the time learned the system the hard way.

And, so, now their kids are older and they have more time and they help other parents navigate the system. So, instead of just somebody helping, it's somebody helping that has a personal history of going through it.

DR. BARNES: That's right. For instance, Donna, in your area, Melanie Tyree Wilson has spent her whole life and energy establishing a community network/web of individuals and she is probably the best resource that you have in your community to be able to direct parents to go and find particular resources and things like that, although, yeah, you're right. It sometimes is very hard to find resources certainly in Lexington and the outlying cities, but sometimes even in Louisville, it's hard to find the resources that take a particular insurance, and that even in Louisville is a barrier.

And the other thing just to point out that Donna may have not alluded to is that the providers who are working in these areas, we try to be resources. We try to talk to as many families as we can, but we are overwhelmed.

So, sometimes that eats into our time to be able to provide advice. We certainly

have opportunities like this in which we get to talk in forums that will get the word out. The Council is another thing, and there are a lot of professionals around the state who have autism expertise, but it's getting the word out in particular areas.

And the most cost-effective way to do that is to create a community and a web, and we're endeavoring to do that at the Council level, certainly the regional Autism Centers that have been part of the KATC consortium in collaboration with OCSHCN. That's also what we've tried to create around those clinics is a web of individuals.

For instance, our nurses who are the autism coordinators in those clinics are a huge source of information and they know parents in the communities who are very, very good, and that really is the most cost-effective way to get the word out about identifying providers who actually have autism training, who are in a specific discipline.

The other thing we didn't talk about is the fact that there are a number of providers that just don't have autism training, whether you're talking about special ed teachers or you're talking about child psychiatrists.

I mean, I have been very lucky

to find some child psychiatry colleagues who work at the Autism Center, but they keep going in and out and David Lohr is now over here. So, it's tough to find people who are trained and who really want to spend their career in this area and that's just a realistic fact.

MS. KALRA: Are there any additional questions?

DR. GRIGSBY: I do think that some school systems are better-equipped than others to handle these children. We had a family come in just Monday who said they've told us we have two weeks to get him on medicines and get him diagnosed or we're going to kick him out of school.

And I said, no, you're not because that's against the law and that is unrealistic for them to put that pressure on you. It's okay. We've got a medical/legal partnership. We will protect him and you until we can get the appropriate thing done for him.

But I think what happens is the school gets exhausted dealing with these children and they don't always know where to turn to get the appropriate services. It wasn't Fayette County. It was a contiguous county.

And it's frustrating because of what had to happen over the period of time that the school got to the point where they even felt like they needed to say that to this family.

DR. BARNES: Exactly. And I think you point out another. It's not necessarily as relevant to some of our funders, although some of our funders do fund services in the schools, but our schools are a huge challenge. They're much better than they were.

We have lots of schools that do really good jobs, but there are literally hundreds and hundreds of schools in the State of Kentucky, and each one of them has anywhere from two to five up to ten individuals with autism of varying severities. And, you're right, there are schools that don't have the background, don't have the training.

The KATC works very hard to do those sorts of trainings and they have a school training process and they do great and it does impact the schools probably in those areas, but they can only do twenty to thirty schools a year, unfortunately. You're talking about hundreds and hundreds of schools.

So, they have a lot of places

where they've not been able to go or in some cases they have not been welcomed which is an unfortunate fact of life as well. There are some areas and schools that don't really any autism-specific training because they're afraid that it's going to end up costing them too much and that's just the bottom line.

So, we still have a lot of tremendous challenges, but I will say that because of the KATC and because of the awareness at the universities, Kentucky is in better shape than a lot of our surrounding states.

It is due to the collaboration at the state level for autism families for all the problems that we talk about. Our families do better than some of those surrounding states and that's because that Kentucky is known nationally for collaborating around the issue of autism and it certainly is due to the hard work that people like Tal and other folks who have really made it their issue over the years.

MS. KALRA: Do you have resources that we could share for school professionals? One of the TAC members on this TAC is a FRYSC and he, I'm sure, would appreciate some of

the resources so he could spread it within his network.

DR. BARNES: I'm sure that if they go to the KATC website, they can find all the school resources they ever wanted. And the same thing is true for the families as well.

On the KATC website, there's a starter guide there. I don't know if you know there's a starter guide there, Donna, but there's a newly diagnosed guide and the first 100 days. There are all sorts of training materials that are on that website. That website gets like 63,000 hits a year. There's a lot of traffic. The newsletter gets about 7,000 families a year.

So, there's a lot of different information that they put on there. The KATC has been around for twenty years now. And, so, the web presence is huge and that website.

If people need further information, they can call the KATC and talk to Mike Miller or Larry Taylor. Mike and Larry are both incredible. They were both Special Ed directors of particular co-ops and they've spent a lot of time in KDE, etcetera working for exceptional children. So, they're really good resources.

MS. KALRA: Great. We appreciate your time here and traveling from Louisville, and you're welcome to stay for the rest of the meeting or head back.

DR. BARNES: Thank you very much.

MS. KALRA: Do we have a quorum now that Dr. Powell arrived? Is it five or six?

MS. HUGHES: You have ten people on your TAC, so, six.

MS. KALRA: So, six. Never mind, then. I was going to ask if we have any recommendations that we want to start talking about after the two presentations that we have.

Is there anything that jumps out that we should recommend or do we want to think about it more thoroughly, let us soak in all this information, but I just wanted to open up the floor to see if there's any recommendations we want to submit to the MAC when we do have a quorum, I should say.

DR. POWELL: I think it's worth reviewing what we talked about last time that Ta presented and today, of course, and trying to come up with some more streamlined recommendations that we

could think about.

MS. KALRA: Do you mind sending your presentation?

DR. BARNES Sure, be happy to send that.

MS. KALRA: I think that would be helpful.

DR. BARNES: Tal, I'm assuming you already sent them your handout as well?

MS. KALRA: Yes. All right. If there's no recommendations, we'll just add this to January's agenda so that way we could have a more deep discussion about recommendations and how we want to move forward with what we heard.

Roundtable updates or concerns from each member/professional organization. Lisa, do you want to go first?

DR. POWELL: Sure. So, one thing that psychologists are following closely, we've had so many CPT changes. You all have heard me talk about concerns about the psych testing changes and codes and now in January CMS just approved we're going to have new what we used to call health and behavior codes, now they will be health and behavior assessment and intervention (HBAI) codes, all new

codes with base codes and, then, add-on codes. So, we're sort of all kind of bracing ourselves wondering how that's going to go and what that's going to mean.

There's going to be some changes to that that I do think will affect intervention. For instance, we used to have those as a fifteen-minute code and now the base is going to be thirty minutes. So, there's some discussion about how that's going to affect intervention. So, for instance, in primary care, I use them often and sometimes it is a short intervention if it's just a followup.

So, I think there's lots of concern just like there was with the changes in the psych testing codes which did create lots of ripples that that's going to happen again in January when the new health and behavior assessment and intervention codes come out. So, I know there's lots of discussion about that right now.

MS. KALRA: Thank you. Donna.

DR. GRIGSBY: Actually, there wasn't a lot, but when I talked with the president of the Kentucky chapter, the one thing he mentioned was the growing concern around adolescent mental health services and suicide prevention and having adequate

numbers of providers but also adequate reimbursement for referring those people for services, those families for services.

And, so, that's something, I think, that the AAP is looking at and is very concerned particularly with the growing number of suicides and even in younger children, pre-adolescents.

DR. BARNES: Louisville, third largest number of teen suicides in the nation. Suicide is the second cause of death in autistic adults. So, it's a huge, huge problem.

MS. POWELL: So, just a followup question. So, is that concern that there are not providers to refer to or the way those providers are able to bill for that, like a crisis intervention or something?

DR. GRIGSBY: It's a little bit of both. It's that there aren't enough providers, and certainly crisis management, it might be a little easier to deal with because there are places for most of these children to get emergently hospitalized but it's those followup services and how those providers are reimbursed and available. So, it's a little bit of both actually.

MS. KALRA: Is there any, like, pilot or data that you all are looking at? What's the next steps with that?

DR. GRIGSBY: You know, it's interesting. In Lexington, there's actually a move toward incorporating more mental health services in school-based clinics. So, that's something that they're working on with a partnership in Fayette County with providers through our adolescent medicine and the school-based clinics.

DR. BARNES: That might be a very good model.

DR. GRIGSBY: And just having adequate counselors in the school-based clinics. And, Judy, you may want to comment on that.

DR. THERIOT: And they're doing a big push right now in Jefferson County for the same thing.

DR. BARNES: So, they're doing the same thing in Jefferson County.

DR. GRIGSBY: And you've probably heard about that in your role.

DR. THERIOT: Yes.

DR. GRIGSBY: I didn't know if there was anything you wanted to add.

DR. THERIOT: No. It's just needed. It's just trying to find ways to provide the service.

DR. POWELL: And I think one of the biggest issues is just the stepdown care, that there's not much in between, just regular, standard behavioral health treatment, hospitalization, but there's got to be lots in between and we don't have as much intensive outpatient, day programs, like you said, people who have training and ability to see kids more intensively which they need.

DR. BARNES: And this is the same problem, we actually had mentioned it, but it's the same problem we have in the autism world. We have kids who get hospitalized acutely for suicidal ideation and other things and, then, they're just sort of released with no plans and they have insurances that don't allow them to access a lot of plans.

Oftentimes, the psychiatrists just give them a list of providers and they call those providers and they get no response from the providers. It's just a real frustrating situation.

DR. GRIGSBY: And one of the things we see in our area and you may see it in

Louisville, too, is they will be acutely hospitalized. They'll be started on medication and, then, they will be told on discharge go follow up with your primary care physician who will prescribe these medications.

DR. BARNES: Yeah, right.

DR. GRIGSBY: And we're sort of like, what, because we don't have the training or the expertise to know how to appropriately handle some of those medications. So, that's a huge gap and a big area of frustration for primary care physicians who have these patients.

And, then, the families get caught in the middle because they're running out of medication and there's no one that's trained to handle that.

DR. THERIOT: And that happens in Louisville all the time and, then, the pediatrician is caught bridging them with prescriptions because the medicine is helping but you're taking on that liability when you do that.

DR. BARNES: And you really don't know what to look for if things go south and all those sorts of things.

MS. KALRA: Pat, do you have

any updates from the nurses?

MS. GLASS: For the school nurses, actually, I'm looking at your pending topics at the bottom of the agenda. Those are things that we are all looking into.

The Kentucky Center for School Safety, I serve on that board as representing school nurses and we're looking at Senate Bill 1 and how that money is going to be spent.

And what Dr. Grigsby is talking about is the same thing that we see. We have students, many more diagnoses of anxiety, school phobias, things along that line and they will go for inpatient and, then, they're released and go back in to the schools and they're not ready.

We have been contracting with more agencies who can come in to the schools and provide some counseling services because that's much easier than leaving school.

They're already there for that, but we do get into an issue with school counselors who unfortunately have a lot of other things assigned to them and they truly aren't able to do the counseling that they are actually hired to do. So, that's where we are.

MS. KALRA: Do you have anything, Cherie?

MS. DIMAR: We had advocacy training a week ago and many of our leaders have had children with autism and they understand and value the advocacy piece of having a child with those needs. And I've seen over the years many wonderful PTA leaders in the schools and have stuff done through their great leadership.

I'm also on that School Safety Committee. So, that school safety funding is critical. Another issue is child abuses, and on the health, safety and welfare side, those issues are very important to us, too.

MS. KALRA: On KYA's radar, our Kids Count County Data Book is coming out next Tuesday. Right now there's a media embargo. So, if you're a member of the media, you could get access early, but other than that, it will be unveiled next Tuesday.

And, so, that is seventeen child well-being data measures that are county level that will be released, and, then, on our Kids Count website, there's a whole section, plethora of data that you could kind of dive into.

And we'll have county profiles as well, so, if you all are interested in county profiles and learning more what's happening in your community, feel free to reach out to me and I could get those out to you.

Also, our Blueprint for Kentucky's Children Policy Agenda will be unveiled December 3rd. So, that's our comprehensive policy agenda which has several measures that we're talking about, school safety being one, free care being another topic, seeing implementation of that, vaping, Tobacco 21, all of those issues being a part of our agenda, child abuse and neglect, thinking of what we could do on that front.

So, that comprehensive policy agenda will be released December 3rd. So, I will shoot that out to partners here so that way you all are familiar with what we're advocating for this legislative session.

And, then, our Child Advocacy Day at the Capitol is January 23rd, I believe. That is the largest rally in Frankfort for child advocates. We have like close to 1,000 people there every year. So, I would love to see many familiar faces and partners out.

Other than that, I can't think of anything that's popping up. I know we're really excited about the free care announcement that happened this past week. We know that when we're talking about behavioral health services or any other health services that that's really going to bridge a gap for those kids that often have those barriers in accessing care.

So, seeing if there's ways to partner with psychologists or other behavioral health folks to be at the school setting to provide the care that's truly needed, we're just really excited and animated by that, and I think that could help with Senate Bill 1 and a lot of that anxiety and depression and other symptoms that we're seeing at a younger and younger age.

Let's go into Old Business. I know I just mentioned free care. Sharley, is there anything else around free care?

MS. HUGHES: The State Plan Amendment was approved last week. CMS did go there. We're still working with KDE on getting the word out. They have been partnering with, as you know, Kristi Putnam and the Secretary. So, they can start providing those services back to August 1st. It was

approved effective for August. So, if they've been providing any of the services, they can start billing and so forth and everything now, too.

MS. KALRA: Is there an FAQ that has been developed? I know we developed like a short FAQ that kind of gives an overall like what is free care, how does this help, what kind of services are covered and providers, but is there anything more than that that has been developed?

MS. HUGHES: I have not seen anything. I think KDE may be doing a lot of communications with the school boards and stuff on this. So, they may have developed some information.

MS. KALRA: If there is, do you mind sharing it out to us so that way we could all let our networks know that this resource is available as we probably field a lot of those questions within our networks?

MS. HUGHES: Sure.

MS. KALRA: Is there anything new on KI-HIPP?

MS. HUGHES: We did send out I think it was last week or maybe the week before about twenty--I don't know how many. Basically, it was targeting all of the waiver program participants

which probably a lot of them will have more eligibility because so many of the waiver beneficiaries, the parents may work and have access to group health insurance and maybe the parents and the rest of the family is not even on Medicaid but the child is. So, therefore, if it's feasible, we could pay the whole family's insurance in order for that child to be covered under.

So, I think that went out last week or the week before. I want to say there's around 20,000 letters but there's been so many numbers around lately; but other than that, I don't think there's been anything else.

They are looking at - and I think this is possibly going to be April 1 of next year - a member that participates in KI-HIPP will only have to submit their proof of other insurance once a quarter. Rather than sending us a pay stub for every pay period, they will just submit the final pay stub for the quarter and we'll be able to go from there. So, that is one change that we're looking at down the road.

MS. KALRA: And it would be effective April 1?

MS. HUGHES: Yes.

MS. HUGHES: There was something else but my mind is just--there were two things that they were proposing and I cannot think of the other one, but there's around 300 signed up so far but I look to see those numbers probably increasing with the waiver population letters going out.

MS. KALRA: Thank you. Any other DMS updates?

MS. HUGHES: No. It's just really busy. The free care, it's just been kind of crazy and now we're just kind of waiting after last week and seeing what transpires and so forth and see where we're going.

MS. KALRA: I think we're all just waiting to see where we're going.

MS. HUGHES: I don't have any information on the RFP. That's not been released yet. So, other than that, we're just----

DR. THERIOT: We've got nothing.

MS. HUGHES: You would think we have a whole lot more and we probably do that I'm not aware of.

MS. KALRA: No. You're totally

fine. I'm sure if it comes to you, you will let us know.

I know we didn't have any data requests or questions for the MCOs, but if there's any MCO updates, I'm happy to open the floor. A lot of MCOs shaking their head no. All right. That answers that question.

General governance. We talked about our meeting dates for 2020. So, we all have that listed. Lisa, I'll make sure that you get them.

Any other business that we want to talk about? All right. We're adjourned.

MEETING ADJOURNED